

# PostScript

## LETTERS

### Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer's disease

I note with interest the Controversy regarding a baby born free of an inherited predisposition to early onset Alzheimer's disease through the use of preimplantation genetic diagnosis (PGD).<sup>1,2</sup> As the medical geneticist for the PGD programme for single gene disorders in Melbourne, Australia, I have seen many couples who have considered PGD for a wide range of genetic conditions. My observation is that many couples look to PGD for "milder" conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination of pregnancy.

An example of this is that in the last 11 years our unit has undertaken 13 prenatal diagnoses for Huntington's disease from nine couples, whereas in the two years that we have been offering it we have had six requests for PGD for Huntington's disease and three couples have already had IVF cycles.

I have a number of concerns with the argument that the woman should not have a child utilising PGD because she is predisposed to Alzheimer's disease.<sup>3</sup> Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If this were the case, what lengths should be gone to to prevent the woman becoming pregnant by natural means? If the commentators who make this argument agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder from having children by natural means, then assisting them to have children not predisposed to a genetic disorder is in my view entirely ethically acceptable.

The concerns for the child of having a mother suffer from early onset Alzheimer's disease are that they will not have a mother to bring them up and the impact this will have. While members of the woman's family have developed disease in their 30s and 40s, this is by no means certain for the woman herself. The only other report of people with this mutation also had early onset Alzheimer's disease,<sup>4</sup> but the numbers affected are very few, perhaps too few from which to draw a definitive conclusion about the exact age of onset for those with this mutation. For example the average of onset of the Val717Ile mutation is 57 years.<sup>5</sup> This is a mutation involving the same amino acid (valine at position 717) and the substitution is for a chemically very similar amino acid (isoleucine compared to leucine). If the destiny of this particular woman is to develop Alzheimer's disease in her mid 40s or beyond then her child will be an adult by the time she is severely affected. Even if we assume that onset of symptoms will be when the child is about 10 years old, the family are aware of this risk and can take steps to be prepared and put in place plans for this. Are couples with other sociological risk factors that put a child at risk of emotional deprivation prevented from utilising reproductive technology? In Aus-

tralia at least, those who are from low income brackets or who use illicit drugs are not precluded from assisted reproductive technology, yet both these factors are associated with a number of poorer outcome measures for children.<sup>6,7</sup>

Finally, PGD is a major undertaking for families. It is a protracted, expensive, and very stressful process and ultimately there is no guarantee that a child will be born through using it. Many couples who consider utilising PGD do not go through with the process for these reasons and choose other reproductive options, including traditional prenatal diagnosis, and natural pregnancy with no intervention, or they decide against having children. Therefore families who undertake this process are generally highly motivated and, one intuitively feels that the resultant child is less likely to suffer social deprivation. This issue will only be resolved by long term follow up studies.

In conclusion, I believe that PGD is ideally suited to situations where families wish to avoid their child having a genetic disease, but where they feel uncomfortable about terminating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.

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## Electronic submissions to the Journal of Medical Ethics

At the time of writing there appear to have been no electronic submissions to the *Journal of Medical Ethics*. It seems appropriate, therefore, to begin electronic correspondence with

a consideration of some of the ethical implications of this new form of ethical dialogue.

I have posted this response to Kenneth Boyd's editorial on Mrs Pretty and Ms B<sup>1</sup> as this article may provoke debate far beyond the medical and ethical establishment. This issue may be of tremendous concern to patients or their carers who are presently suffering in circumstances similar to those described.

The electronic response forum of the BMJ has been in operation for over four years.<sup>2</sup> An editorial in the BMJ on physician assisted suicide<sup>3</sup> has attracted 125 responses at the time of writing. An important feature of electronic responses, particularly on items that generate a lot of debate, is that the contributions often refer to each other. These responses range from the scholarly and meticulously argued to distressing personal accounts of suffering. As both an avid reader of rapid responses to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them should be when I wish to enter into dialogue with the author. I feel on sure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing up a response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to approach distressing accounts of suffering with a degree of empathy. It is sometimes the case, however, that submissions clearly showing distress also contain dubious argument that any peer review process would deal with severely.<sup>4</sup> Where accounts of suffering alongside dubious arguments are posted from patients I personally feel squeamish about responding, finding myself caught between the roles of vituperative reviewer and empathic listener. As an editorial in the BMJ on the subject of electronic responses has noted: "We've begun to capture the opinions and experience of patients ... and publish just about anything that isn't libellous or doesn't breach patient confidentiality".<sup>2</sup> Inevitably, such a broad range of responses will produce many that deserve to be challenged. Merely to ignore dubious argument implies that such opinions are correct. Furthermore, it is astonishingly easy to post an electronic response, and the process contains no warning that opinions expressed may be severely challenged. We should consider what the rules of debate on this *Journal of Medical Ethics* web site should be.

To prevent any misunderstanding, I wish to state that this response does not issue out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don't ignore me.

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### Editor's response

Dr Lewis raises the important issue of what the rules of debate should be in electronic correspondence.<sup>1</sup>

As an editor, I feel as if I am caught in the maelstrom of evolution. The web has radically changed the nature of debate and the presentation of information and knowledge. It is not clear to me how and whether it should be controlled. My general approach has been to let the experiment run in a free way and look at the results. Then it will be clearer what rules are required.

Electronic correspondence, for me, is different from scholarly debate. It takes advantage of the web's accessibility to give people the opportunity to express their own views and to see the range of views on a particular issue. At present, the *JME* operates on the principle that it will publish electronically any response which is not libellous or harmful in other ways. Electronic letters which contribute significantly to the debate (such as Dr Lewis's letter) may be selected for publication in the paper version of the journal.

The core business of a journal such as the *JME* should be the publication of scholarly articles which contribute to knowledge. But as a medical ethics journal, it should also be engaging and relevant to professionals and non-professionals. We have introduced a current controversy section which reports an issue of contemporary interest and we solicit off the cuff comment from people who may have an interesting view on that topic. Electronic correspondence should serve a similar function: to increase people's interaction with the journal and with others.

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## BOOK REVIEWS



### In Two Minds: A Casebook of Psychiatric Ethics

D Dickenson, Bill (KWM) Fulford. Oxford University Press, 2000, £27.50, pp 382. ISBN 0-19-26-28-58-5

Although the title describes this as a "case-book", it is much more than that. The casebook format entices the reader into a series of readily accessible discussions of increasing complexity and erudition until a vast landscape of medical ethics is evoked and in many instances the very bedrock of morality exposed. The authors seem effortlessly to

introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The centre-piece of the book is undoubtedly a series of well-chosen cases (thematically progressing from diagnosis to management and prognosis), each followed by an extensive analysis of the ethical issues, including contrasting arguments from different vantage points. There then follows a commentary by a practitioner with relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is rounded off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal cases.

The book is extraordinarily innovative in many respects. Not only is the case history and analysis format interesting and methodologically robust, but the case material is so challenging and the ethical analyses so wide ranging and scholarly that it is difficult to put this book down! One discovers how different analytical strategies lead to progressively deeper levels of understanding of the ethical issues, thus exposing "the heart of the matter"; along the way one is referred to books, chapters, and articles for further reading. As might be expected, Fulford's notion that an explicit analysis of values is helpful in defining diagnostic concepts in all areas of medicine is a recurring theme. Dickenson's interest in informed consent (also in children), "moral luck", and her feminist reconstruction of rationality, are drawn upon in several sections.

Several of the clinical cases are "grey area" cases—cases that do not easily fit into clear diagnostic slots, where clinicians disagree about the precise diagnosis and may start doubting their own judgment. For example, the question of the differential diagnosis of a man who appears to have a religious delusion, yet leads a very successful professional life turns "not on the facts about his experiences and behaviour, but on a series of value judgements". The authors point out that the diagnosis of schizophrenia in the DSM-IV (a widely used diagnostic classification system) requires the criterion of "social/occupational dysfunction... below the level achieved prior to the onset". Here a paradox is demonstrated: the evaluation of "social dysfunction" depends on values, yet the authors of the DSM-IV claim that the system was "grounded in empirical evidence"! The reader is challenged to come to terms with the value related elements of the diagnosis of schizophrenia and related diagnoses. As with several other cases, the importance of a team approach is emphasised, bringing to bear, as it should, a variety of perspectives that may include elements of cultural formulation and the patient's values.

Other chapters address teamwork and service organisation, and research ethics; a section on wider perspectives gives an international view; in an interesting chapter Fulford describes the basis for his belief that psychiatry can take the lead in bioethics, "providing lessons for medicine as a whole". There is also a useful sample teaching seminar, showing how theory is put into practice.

This book will appeal to any reader who wishes to escape from the well-worn path of "four principles plus". It is likely to be enriching to psychiatrists who feel that the DSM-IV and ICD-10 are constrained not so much by limitations of their science, but of their humanities. It provides thoughtful material

for those interested in finding a way of resolving the tensions between physical medicine, psychiatry, and ethics. The book is a treasure trove of annotated bibliographies and very enjoyable to read.

**S Louw**

### Ethical Issues in Palliative Care—Reflections and Considerations

Edited by P Webb. Hochland and Hochland, 2000, £15.95, Pp 138. ISBN 1-898507-27-9

This book is a collection of essays by a variety of specialists with a particular interest in palliative care. It contains seven chapters by six different authors.

The first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in palliative care with a background in nursing. She tells us that studying ethics encourages logical reasoned thinking in the face of difficult decisions such as allocation of resources, access to services, best care, clinical research, and rights to life. Webb reminds us that clinical guidelines may not be much help in the face of an ethical dilemma with no clear right or wrong answer.

The chapter called Care versus cure by David Jeffrey, a consultant in palliative medicine and writer on medical ethics, reminds us that care is concerned as much with the subjective feelings of the patient as with the physical disease, and aims to relieve suffering and improve quality of life. He emphasises that by sharing the reality of uncertainty (with patient, family, and colleagues) we can make more realistic decisions, and that informed consent is a mechanism for sharing the power of doctors and patients.

Giving it straight—the limits of honesty and deception by Heather Draper, a lecturer in biomedical ethics, explores the difference between truth-telling and honesty, and between honest and dishonest selective truthfulness. "There is a sense in which we are always selective with the truth", she writes and reminds me of the saying so useful in palliative care that: "Truth like medicine can be skilfully used, respecting its potential to help and to harm".

The chapter on Advocacy by Patricia Webb defines advocacy as "the role of one with expertise who is invited to negotiate on behalf of another", and is an interesting analysis of the power differences between patients and professionals. She makes the point that "patients have little power to influence the nature of care provision unless a determined effort is made to reduce their actual and perceived vulnerability". She also emphasises, however, that skilful communication allows most patients to be directly involved in decision making. With good team care few patients need an advocate, except those few who prefer to be very passive, or who are unable to make decisions, such as those with severe learning difficulties.

The next chapter, How informed consent be?, by Calliope Farsides, a senior lecturer in medical ethics, makes the point that it is often useful to consider consent not primarily as a legal concept but a moral one, and one that depends on the relationship between patient and carer being a relationship of trust, reciprocity, and beneficence, with mutual recognition of their duties and obligations. She goes on to look at the differences between